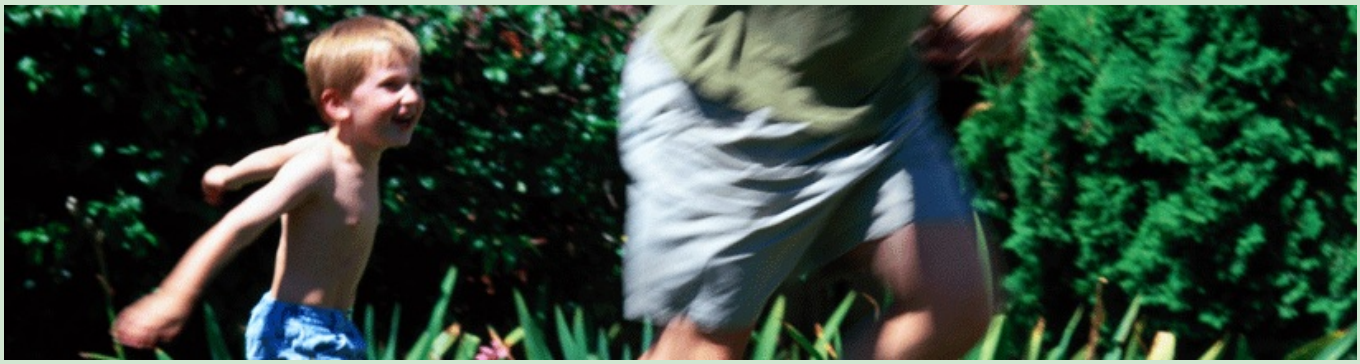
Neuropathy Action Foundation

Awareness ▪ Education ▪ Empowerment

Patient Voice - March 2021 Issue **Visit our Website**



In this Issue

Dear Scott,

When it comes to treating the over 100 different types of neuropathy, out-of-pocket costs can put medications out of reach for some patients. Worse, pharmacy benefit companies increasingly are restricting the list of drugs they will cover, leaving patients to pay the full cost of the medication they need. Consider, too, that neuropathy is a chronic disease, often requiring ongoing treatment. It's no wonder why the NAF receives so many calls from patients worried about access to their medications.

There is help. Most drug companies have various Prescription Assistance Programs. Additionally there are non-profit organizations that offer various types of assistance ranging from free medications

to help with deductibles, coinsurance, loss of insurance, transportation and preservation of finances.

The NAF recently created a document that lists various assistance programs that we help will allow you to continue or obtain your needed treatments and medications.

Best Wishes,
Dominick V. Spatafora
Founder and Presiden

To view the financial assistance programs document **click here**.

U.S. FDA Approves PANZYGA® for the Treatment of Adults with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Friday, February 12, 2021 - 05:10pm

The first and only FDA-approved intravenous immunoglobulin with two maintenance dosing options for CIDP

NEW YORK--(BUSINESS WIRE)-- Pfizer Inc. (NYSE: PFE) today announced that the U.S. Food and Drug Administration (FDA) has approved the supplemental Biologics License Application (sBLA) for PANZYGA® (Immune Globulin Intravenous [Human] – ifas 10% Liquid Preparation) to treat adult patients with a rare neurological disease of the peripheral nerves called chronic inflammatory demyelinating polyneuropathy (CIDP).

PANZYGA is the only intravenous immunoglobulin (IVIg) with two FDA-approved maintenance dosing options for CIDP, helping to meet the clinical needs of patients. PANZYGA can also be administered at infusion rates up to 12 mg/kg/min.

“Each patient with CIDP has different treatment needs, and we have found that having one approved dosing option is not always optimal,” said Angela Lukin, Global President, Hospital Business Unit, Pfizer Inc. “The approval of this new indication with additional dosing options helps address an unmet patient need by providing healthcare providers with the ability to choose an approved dose that's right for patients.”

CIDP is a rare disorder of the peripheral nerves characterized by gradually

Multifocal Motor Neuropathy (MMN) Education Reached Millions

Following a successful MMN campaign in 2019 that resulted in three outstanding patient videos, thousands of new grassroots advocates, and over 1 million ad impressions the NAF embarked on a new and exciting MMN awareness campaign in 2020. In 2020 the NAF continued to educate around MMN and raise awareness of the impact of the disease to neurologists, potential patients, as well as the general public. The project was a huge success and was completed in late 2020. Out goals and accomplishments are highlighted below.

Increase General Awareness of MMN Through Creative Content
The NAF launched a three-month digital campaign across Facebook and Twitter to educate and raise awareness around the impact of MMN. From July 9 to October 9 the NAF targeted neurologists, those living with MMN, potential patients, as well as the general public. The campaign included ads featuring animation and first-person video testimonials that were created from three MMN patients diverse in age, ethnicity, and from different areas of the country. The NAF served animation and first-person video testimonials across Twitter and Facebook to explain MMN and highlight its impact on patients and their families. The campaign reached 581,093 people and generated 2,773,053 impressions, 1,938,729 three-second video views, and 11,679 clicks, with an overall click-through rate of 0.42%.

Create an Email Series to Educate and Engage New NAF Members
The NAF engaged subscribers that were acquired from the 2019 digital acquisition

increasing symmetrical motor and sensory loss and weakness associated with loss of deep tendon reflexes. It is caused by damage to the covering of the nerves, called myelin.

The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may limit and delay the response to therapy. Most individuals will require long term treatment; nearly a third of CIDP patients will progress to wheelchair dependence if left untreated. Early recognition and proper treatment are critical in helping patients avoid a significant amount of disability.

The approval for this new indication was based on data from a prospective, double-blind, randomized, multi-center Phase 3 study in 142 patients diagnosed with CIDP. This Phase 3 study was the first and only IVIg CIDP treatment study to evaluate more than one maintenance dosing option. Efficacy, safety, and tolerability was observed during seven maintenance infusions at three-week intervals over a six-month period.

The primary efficacy endpoint was the proportion of responders in the 1.0 g/kg PANZYGA treatment arm at six months relative to baseline. A responder was defined as a patient with a decrease of at least one point in the adjusted 10-point Inflammatory Neuropathy Cause and Treatment (INCAT) disability score.

The primary endpoint was met with 80% of patients in the study achieving an INCAT response with the 1.0 g/kg dose. Dose-dependent efficacy was shown by several supporting endpoints, including a 92% response in adjusted INCAT score in the 2.0 g/kg dose arm.

Dose-dependent responses were also demonstrated in the 1.0 g/kg and 2.0 g/kg dose arms in grip strength, Inflammatory Rasch-built Overall Disability Scale (I-RODS) and Medical Research Council (MRC) sum scores. PANZYGA was generally well tolerated. The most common adverse reactions (>5%) across all dosing arms were headache (15%), fever (14%), dermatitis (10%), and blood pressure increase (8%). During the study 11 patients (8%) received premedication.

PANZYGA was approved by the U.S. FDA in 2018 for the treatment of primary immunodeficiency (PI) in patients two years

campaign through a series of emails. Subscribers received three emails that encouraged them to spread awareness of MMN. The emails were sent to 3,300 readers and generated an average 15% open rate and an 11% click rate.

Map and Engage Online Influencers to Share MMN Content with Their Online Audience
The NAF collaborated with two diverse influencers in the health space to raise awareness about MMN to their online audience. The posts shared by the influencers reached an audience that consists of health/medical practitioners with influence in priority demographics. The influencer campaign reached 37,600 people and generated 490,339 impressions and 2,518 engagements, including 2,065 clicks and 84 comments, with an overall click-through rate of 0.40%. The campaign also reached 20% of users between the ages of 18-44 and 80% of users between the ages of 45 plus.

The NAF Applauds Congressional Action to Increase Research

The NAF applauds action taken by Congress to designate “peripheral neuropathy” as a condition eligible for research funding from the Department of Defense (DoD) Peer Reviewed Medical Research Program (PRMRP). Language designating the condition eligible for funding is included in the fiscal year **2021 Omnibus Appropriations Act**. Every year, Congress designates dozens of specific conditions that are eligible for research dollars from the PRMRP, which is funded at $370 million in the Omnibus legislation. Prior to the enactment of this legislation, peripheral neuropathy was never included by Congress as a PRMRP research topic. Thanks to a national advocacy program initiated by the Foundation for Peripheral Neuropathy, Neuropathy Action Foundation, Western Neuropathy Association and other organizations that engaged grassroots advocates across the country, Congress took an interest in the disorder, particularly as it relates to members of the Armed Services and Veterans.

Peripheral neuropathy refers to the many conditions that involve damage to the peripheral nervous system. The disabling

of age and older and chronic immune thrombocytopenia (cITP) in adults.

Pfizer Inc. and Octapharma AG are parties to a license agreement pursuant to which Pfizer is granted rights to market and commercialize PANZYGA in the U.S. Octapharma retains exclusive rights to commercialize this product globally outside of the U.S.

Click here to continue reading.

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symptoms of peripheral neuropathy include poor balance, numbness in hands and feet, significant mobility problems, pain (sometimes severe), sleep difficulties, and muscle weakness, among other symptoms. Peripheral neuropathy is common among the veterans community, particularly those diagnosed with diabetes, hepatitis C, and HIV. Cancer patients who have undergone chemotherapy treatment commonly develop peripheral neuropathy.

Thanks to each of you in the neuropathy community who advocated on behalf of our community.

Keep Your Skin Smooth and Hydrated

With summer quickly approaching many of us will be in the sun more and will therefore experience dry skin. Whether it is caused by aging, an underlying skin condition, or environmental factors, having dry skin can be uncomfortable and itchy. There is a range of treatments available to treat dry skin at home – but which are most effective?

Dry skin, also called xerosis, is skin that lacks moisture in its outer layer. If left untreated, dry skin can crack and become infected. Keeping dry skin moisturized is important, but some store-bought treatments can be expensive or ineffective.

This article explores home remedies for dry skin and looks at the scientific evidence behind the claims -

https://docs.google.com/document/d/1JRz8K6SD4xIoCDk_0bZl-HKXkOKtIED9mMgG_xD-eMI/edit?usp=sharing

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